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ABSTRACT

This newsletter feature issue focuses on quality assurance and innovative efforts to enhance service quality for persons with developmental disabilities. Individual articles include: "Redesigning Quality Assurance" (Clarence J. Sundram); "Quality Assurance, Quality Enhancement" (Charlie Lakin et al.); "Challenging Tradition: Measuring Quality by Outcomes" (James Gardner); "Reinventing Quality" (Gary Smith); "CSLA (Community Supported Living Arrangements) and Quality of Life: Balancing Inclusion, Choice, and Protection" (Michael W. Smull); "Quality in Community Residences: Subcommittee Report" (Robert Gettings); "Quality Enhancement: A Commitment in Pennsylvania" (Nancy Thaler); "Quality Assurance for Quality of Life in Utah" (Georgia Baddley); "Continuous Quality Improvement in Oregon" (Darla Wilson et al.); "A Reorientation to Quality Assurance in New York" (Thomas Cuite); "Service Enhancement through Self Examination in Connecticut" (Joseph Harrison-Becker and Dennis Mitchell); "Performance Contracting for Service Quality in Minnesota" (Robert Meyer); "Consumer Monitoring of Services in Oklahoma" (Dennis Bean and John Gajda); "Gathering Quality Relevant Data in Colorado" (Judy Ruth and Lynne Struxness); "Quality through Direct Service Training in Kansas" (Kathleen Olson); "Improving Quality through Parent and Self Advocate Training" (Colleen Wieck and Thomas J. Zirpoli); "Parent Case Management Training Promotes Quality" (Marijo McBride); and "Action Learning for Quality Improvement" (John O'Brien and Connie Lyle O'Brien). Eleven resources are also listed. (DB)

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Feature Issue on Quality Assurance
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Volume 6 (2) Summer 1993

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**Feature Issue on Quality Assurance** **Volume 6 (2) Summer 1993**

**For Stacy Lockwood and her mother Audrey, as for millions of Americans, quality assurance in community services for persons with developmental disabilities means receiving the supports that make community integration possible.**

# Redesigning Quality Assurance

*by Clarence J. Sundram*

The publication of David Osborne's book, *Reinventing Government*, has spawned a renewed interest in changing the way in which governmental functions are carried out. It has given rise to new initiatives in Washington and in many states to "reinvent the Pentagon" or to "reinvent the Department of Motor Vehicles." This movement towards "reinvention" comes on the heels of an earlier fascination with Total Quality Management (TQM) that placed renewed emphasis on satisfying customers' expectations. These two waves of change have hit the field of developmental disabilities at a time when it is particularly open to change. The waning role of institutions, and the growing experimentation with a variety of community alternatives under Medicaid Home and Community-Based Services Waivers and other federal and state programs, have prompted policymakers to rethink the manner in which government assists in meeting the needs of people with developmental disabilities.

In thinking about redesigning quality assurance in services to persons with developmental disabilities, it is clear to me that one cannot redesign quality assurance without redesigning the service system as well. Thus, the task must start with ensuring that the service system itself is built on a firm foundation that promotes quality. Quality begins with explicitly and honestly articulating the values that undergird the system, and maintaining simple, clear and consistent expectations for performance.

*Redesign, continued on page 22*

## From the Editors

As persons with developmental disabilities move from institutional to community living, day centers to integrated work environments, social isolation to valued participation, and total dependence to greater autonomy, new approaches to assure and enhance service quality are required. In many states, innovative efforts already have resulted in services that are more responsive to the needs and preferences of those they serve.

As innovative quality assurance and enhancement programs evolve, certain common elements emerge: a culture of quality rather than simple regulatory compliance; consumer-centered and value-driven services; decentralized authority and responsibility; multi-stakeholder monitoring; technical assistance before sanctions; and measures of consumers' quality of life rather than providers' quality of effort. Ongoing quality enhancement is, by definition, sustainable. Universal attention to quality of services is not insensitive to resource limitations. Finally, ongoing quality programs have constituencies; they not only do good, they are *known* to do good.

This issue of *IMPACT* offers the perspectives of leaders of innovative efforts to assure and enhance service quality for persons with developmental disabilities. We hope that their ideas and work will inspire and guide others in redefining quality in their own work.

CONTENTS

**National Perspective** 2
**State Efforts** 9
**Training for Quality** 17
**Resources** 21

A publication of the Research and Training Center on Residential Services and Community Living and the Institute on Community Integration (UAP), College of Education, University of Minnesota. Dedicated to improving community services and social supports for persons with disabilities and their families.

# Quality Assurance, Quality Enhancement

*by Charlie Lakin, Bob Prouty, and Gary Smith*

The evolution of our society's response to persons with developmental disabilities over the past quarter century has been driven primarily by the images of dismal conditions in large institutional settings. Those images were created through the vivid written, spoken, and visual essays on institutions by scholars like Burton Blatt, politicians like Robert Kennedy, and media figures like Geraldo Rivera. With institutional life as the referent, this response has brought steady movement of people from the social deprivation of institutions to what was assumed to be a vastly improved life "in the community." For example, nationwide the average daily populations of state institutions decreased from 194,650 people in 1967 to 80,270 people in 1991. Since 1989 there have been more people living in "community" residential settings (places with 15 or fewer residents) than living in institutions with 16 or more people. Nationally, "residential services" have joined educational, vocational, family, and other services in what is primarily a community system.

That most persons with developmental disabilities now live in community settings is more than just an important accomplishment in the movement to assure their place in communities. It has also served as a clarion call to attend in new ways and with greater care to the products of that movement. Recent research has suggested that physical presence alone cannot be equated with meaningful participation and membership in the community. Increasingly people are looking for approaches for identifying and responding to the needs of people that substantially improve the quality of their lives, membership in their communities, ability to control their own lives, and other implied and desired outcomes of community living. But, they want these outcomes while still responding appropriately to the differing types and degrees of vulnerability among people with developmental disabilities. People are also looking for ways to monitor, evaluate, and enhance efforts. This work is being undertaken with a growing sense of urgency.

Several factors contribute to the crisis in confidence in the predominant, existing methods of "quality assurance" and the need to find new ways of defining, monitoring, and enhancing service quality. One is the challenge of the vastness and rapid growth in community services. Service systems have become extremely dispersed, increasing the challenges facing government quality assurance monitoring efforts. In the area of residential services in 1977, there were 11,025 separate households in which persons with developmental disabilities received out-of-family residential services. By 1991, that number had exploded to over 46,000 separate settings in which people received residential services. This growth will continue, and in light of budgetary problems facing most states, few can be expected to grow their quality assurance systems at anywhere near the rate that service settings will grow. To be viable, quality assessment and enhancement systems must become more efficient. They must reduce standards to the essential, eliminate redundancy, and effectively use resources beyond those available within traditional monitoring agencies.

A second factor is the ineffectiveness of traditional "quality assurance" approaches. Current "quality assurance" approaches, which are based on collections of hundreds of detailed standards applied uniformly in every setting monitored, are not producing desired results. Clearly the current approach in "assuring" quality lacks efficacy. Over three-quarters of the federal court rulings and settlements related to constitutionally inadequate institutional care in the past 15 years have involved facilities with ICF-MR certifications, an extremely regulated program. The current approach also lacks reliability. Given the same setting, different monitors cite different deficiencies. Finally, the current approach lacks validity. One often cannot distinguish, in quality of life measures, between residents of group homes that are ICF-MR certified and those that are not. While the standards in quality assurance processes associated with the ICF-MR program are intended to cause dozens of good outcomes (safety, comfort, freedom from exploitation, opportunities to learn, therapies as needed, good diet, etc.), as written and implemented they may unduly emphasize paperwork, environment, and health and safety at the expense of other quality of life measures.

A third factor is the recognition that quality is different in different settings and for different people. There is great diversity in what different types of services are trying to accomplish generally and in what specific plans are trying to accomplish for different individuals. Standards to determine whether there is adequate quality in services delivered in different settings and even to different people within the same setting must be sensitive to this challenging but fundamental reality. The rapid growth in Medicaid Home and Community-Based Services for persons with developmental disabilities (from 0 in Fiscal Year 1981 to a projected 98,000 in Fiscal Year 1993), the new (1991) Medicaid Community Supported Living Arrangement services, and other individualized, services-based rather than facility-based programs, reflect a growing acceptance of the proposition that quality in services is as much or more determined by the extent to which the nature, amount, and timing of service accommodates the individual's specific needs and life circumstances as it is by any inherent "quality".

The fourth factor is the increasing focus on quality of

life for persons with developmental disabilities. Virtually all definitions of quality of life recognize that there is no single standard, but that each individual's needs, interests, and preferences play a major role in any individual's definition of quality of life. This reality, recognized in formal research on quality of life, has had little place in the past efforts at defining and monitoring quality of services for persons with developmental disabilities. Past "quality assurance" efforts have focused on physical, staffing or programs standards that would seldom be included in any individual's definition of important aspects of quality of life. For example, quality in human services is increasingly viewed not as a status to be assessed and certified, but as a process in which a person with disabilities, service provider(s), family, friends, and others articulate life goals, establish a plan for reaching those goals, and work effectively toward those goals. Quality is thereby manifested in the achievement of desired outcomes.

Yet another factor is the sense that quality assurance and monitoring should contribute to improved services. A recent report of the U.S. General Accounting Office (1990) focusing on quality assurance in health care contained an observation that is highly relevant to services for persons with developmental disabilities:

> Quality assurance systems typically concentrate on quality assessment and the identification of the relatively small number of providers whose care is obviously unacceptable. They do comparatively little in attempting to directly improve the overall levels of quality provided by the majority of health professionals....If we think of performance of health care providers in terms of the bell-shaped curve of a normal distribution, the challenge is to devise a quality assurance strategy that not only deals appropriately with the outliers but also assists in moving the entire distribution to a higher level of quality.

Service delivery enhancement activities are those activities provided to improve the quality of delivery of the services received by persons with developmental disabilities beyond the minimum levels assured by current regulatory practices. Quality assessment systems and the enhancement systems linked to them must focus on and have access to the variables and resources that can actually improve quality. Quality assessment and enhancement efforts must be formative as well as summative in focus.

An additional factor is recognition that people with developmental disabilities are vulnerable to abuse and neglect in the community. There is a substantial challenge in recognizing that with personalization of services, supports, training, and opportunities for individuals comes the challenge of personalizing quality assessment and enhancement activities. Replacing current approaches to "quality assurance" must not be done flippantly. Persons with developmental disabilities are vulnerable to neglect, exploitation, and abuse. The documented record of actual abuse and neglect is clear; it happens within the current quality assurance efforts and it can happen or even increase under alternative approaches. Therefore, when improving approaches to quality assessment and enhancement, in addition to addressing the more personalized aspects of quality of life, basic health and safety standards must be established. These must assure that when the individual is not independently self sufficient that appropriate steps have been taken to protect the individual and/or to guarantee actual delivery of needed supports, services, training, and/or opportunities.

A final factor is the growing recognition that quality is best measured in "outcomes," not "structures" or "processes." Writing about quality in medical care 25 years ago, Donabedian (1966) developed a three-dimensional framework for the assessment of quality that included: 1) structure, 2) process, and 3) outcome. In his model, *structure* includes administrative and related processes that support and direct the provision of care. These inputs are largely administrative creations of the program or agencies providing oversight. *Process* includes information gathered and recorded related to assessment of skills and needs, services provided and implemented, unique individual occurrences including crises and staff responses to crises, medical needs and services received, staff training, interagency meetings regarding the individual, and so forth. *Outcomes* include measurable effects of the services received or needed. In services for persons with developmental disabilities these outcomes might be found in areas such as personal developmental objectives achieved, social skills practiced, social relationships maintained, types and frequency of community participation, improved employment and earnings, increased self-determination and choice, consumer and family satisfaction, and reduced costs for benefits.

Increasing numbers of people are recognizing, as Donabedian recognized a quarter century ago, that quality of services is ultimately found in their outcomes, not in the structure and process variables of presumed value. There is urgency in moving to outcome-based assessment and enhancement of quality, and yet caution about people's vulnerabilities must govern our trials of new approaches. We must share ideas and concerns and provide opportunities to learn from each other.

*Charlie Lakin is Director of the Research and Training Center on Residential Services and Community Living, University of Minnesota, and Bob Prouty is on the staff of the center. Gary Smith is Director of Special Projects with the National Association of State Directors of Developmental Disabilities Services, Inc., Alexandria, Virginia.*

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# Challenging Tradition: Measuring Quality by Outcomes

*by James Gardner*

With the publication of the new Outcome Based Performance Measures, The Accreditation Council signals a new focus and offers a new challenge to the traditional approach to quality assurance. The Outcome Based Performance Measures reflect a dramatic shift in the definition and approach to quality in services for people with disabilities. The measures consist of priority outcomes that people with disabilities indicate are most important to them, and include 30 specific items such as individual choice, dignity, respect, social inclusion, security, personal relationships, rights, insurance, and satisfaction. These outcomes for people transcend particular programs and services. Outcome measures contain no reference to work, vocational training, particular residential setting, leisure activity, clinical setting, or other program specific language. They are generic and apply to all supports and services provided to people with disabilities.

**The focus on outcomes brings the person into the quality improvement process.**

This fundamental change began in 1990 when The Accreditation Council shifted from a traditional focus on quality assurance through accreditation to one that emphasizes the enhancement of quality. The Council expanded its mission to include working with agencies to improve the quality of supports and services to people with disabilities instead of keeping activities limited to service evaluation. The new mission of The Council is that of a "national quality improvement organization." This change in the mission of The Council and the content of its standards reflects changes in the field of disability. During the past quarter century our knowledge base has increased, our practice has become more promising, and we have gained greater experience working in partnership with people who experience disabilities.

During this time, the relative emphasis placed on the traditional input, process, and outcome indicators has changed. The early focus on input and process measures occurred because the field was not certain of the outcomes that could be expected or that those outcomes could even be measured. In the absence of clearly defined outcomes, standards and regulations stressed organizational inputs and process. The following categories identify the traditional quality assurance indicators:

- *Input* measures that focus attention on resources such as physical environment, financial support, people and technology that are put into a program. Standards that focus on square footage of living space in a bedroom, the per diem rate, or the number of full time staff are concerned with inputs.
- *Process* measures that focus on how the inputs are used and arranged, and that describe how the organization operates. Standards that specify team member interaction or describe how planning decisions are recorded, reported, and reviewed are process oriented.
- *Program Outcomes* measures that describe the end result, not the resources or the means to accomplish the end. Program outcomes target service goals, such as the number of work placements.

*Outcomes for people*, however, describe the outcomes that make the greatest difference to people receiving the service or support. The Council views quality not as compliance with program requirements, but rather as responsiveness to individual outcomes. In the past, input and process standards became ends in themselves. Input and process indicators were developed for specific programs. As a result, residential, vocational, social, and educational standards evolved around programs. Quality was defined as the extent of the program's compliance with its assigned input and process measures. Standards for particular programs were not connected to the people in the programs. In refocusing on outcomes for people, The Accreditation Council is not abandoning important input or process requirements. Organizations need qualified staff, along with policies and procedures. However, The Council maintains that outcomes for people are more important that input or process standards.

**This new emphasis on outcomes for the individual, rather than organizational process, challenges traditional approaches to quality assurance.**

Three major factors motivated The Council to question its own traditional approach to quality. First, board members and staff recognized that there was an unfortunate and disturbing outcome of the program approach to services. Quality efforts that emphasized process in programs resulted in the development of uniform programs being offered to serve many unique and different people. People were often

pigeon-holed in the best available program "slot" and services focused on supporting the person to succeed within the chosen environment. As an alternative to program thinking, some providers began to offer individualized services and supports to people instead of placement in programs. The transition from a focus on "programs" to a focus on people was the seed of a new definition of quality that identifies outcomes for people as the primary variables, instead of conformance with program or professional criteria.

The recognition of people with disabilities as the primary stakeholders in the service process was the second critical factor motivating change. This new focus on individuals decreased the relative importance of input and process measures and increased the attention to outcomes for people. The identification of the person as the key stakeholder also solved the question of what to measure. People with disabilities identified what they expected from their service and supports. Outcomes for people demanded a higher priority than employing the proper process or the right combination of inputs.

Finally, this change in human services was reinforced by the growing evidence from the general service economy that services of quality attend and respond to the need of the customer. In fact, the customer's needs and opinions are not only sought, but they are also highly valued. Indeed, quality can be defined as the extent to which a service meets or exceeds the customer's expectations.

This new emphasis on outcomes for the individual rather than organizational process challenges traditional approaches to quality assurance. "Responsiveness to the person" will provide greater urgency and clarity of purpose than conformity and compliance. The focus on outcomes brings the person with disabilities into the quality improvement process.

*Jim Gardner is Executive Director of The Accreditation Council on Services for Persons with Disabilities, Landover, Maryland.*

# Reinventing Quality

*by Gary Smith*

Over the past decade there has been enormous change in the topology of publicly-funded services and supports for people with developmental disabilities. Ten years ago, most people who received residential supports lived in large, typically state-operated congregate care facilities. Today, the majority are supported in small community living arrangements, and many participate in community employment and recreation options, and family life.

The past decade also has seen a fundamental shift in the service paradigm. The rigid "continuum of care" is giving way to the "supports paradigm." We are moving away from "care and treatment" program models and specialized facilities, to systems that are propelled by personalized support strategies embracing community membership, personal choice, integration, interdependence, and diversity.

Against this backdrop of system reconfiguration and redefinition, there is growing recognition that how we promote high quality services also must change. The diversification, decentralization, and sheer growth of community service systems call into question the viability of quality assurance systems that principally rely on traditional methods. For example, formal survey and inspection processes cannot keep pace with the growth in service settings. Moreover, as supports are increasingly furnished outside the confines of specialized facilities, yesterday's standards of best practice are malaligned with the new paradigm. Additionally, prescriptive regulations stand in the way of personalizing support strategies. The interplay of personal choice, natural support networks, and regular community living enormously alters the framework within which we judge the quality and effectiveness of community services.

Solving the "quality equation" poses enormous challenges. These challenges will not be met by simply hiring more inspectors or promulgating additional regulations to surround community services with formalized quality assurance systems. Approaches are needed that recognize that quality is not a status to be assessed and certified, but a process in which a person with disabilities, service provider(s), family, friends and others articulate life goals, establish a place for reaching those goals, and work effectively toward them. Quality must be measured in terms of whether service systems are achieving valued outcomes in areas such as personal development, community participation, self determination, economic independence, consumer and family satisfaction, and improved efficiency. We are reinventing how we support people with developmental disabilities; it is time to reinvent how we judge the results of those supports.

*Gary Smith is Director of Special Projects with the National Association of State Directors of Developmental Disabilities Services, Inc., Alexandria, Virginia.*

# CSLA and Quality of Life: Balancing Inclusion, Choice, and Protection

*by Michael W. Smull*

In 1990, Congress granted authority for eight states to provide community supported living arrangements to Medicaid eligible citizens with cognitive and/or physical disabilities. The congressional action that created Community Supported Living Arrangements (CSLA) reflected the tension between the desire to promote choice and the need to protect vulnerable individuals. This was carried into the request for state proposals to participate, which included the explicit requirement that the state, "show how it intends to balance between recipient choice and the state's responsibility to protect the health and welfare of the recipients." Regardless of the severity of the disability, people with developmental disabilities are more vulnerable and deserve protections that exceed those accorded to other citizens. Reasonable protections must be ensured without denying individuals opportunities to choose from the lifestyles typically available in their communities. Implicit in these efforts is a new definition of quality of life for people with disabilities and a new struggle to make scattered examples of excellence in supported living the service norm.

The congressional action that created Community Supported Living Arrangements reflected the tension between the desire to promote choice and the need to protect vulnerable individuals.

Quality of life is subjective; it is defined and redefined by each of us over the course of our lives. People with disabilities want qualities in their lives that are like those of their fellow citizens. They want lives that are as varied, as rich in texture, occasionally as eccentric, but mostly as typical. People with disabilities want lives that reflect their preferences and desires, regardless of whether or not they can speak for themselves. Systems of support must include people who are skilled at "listening" to words and behavior and understanding the individual. And those systems must keep listening because what is wanted today is often not what is wanted tomorrow.

With these things in mind, CSLA services should begin with choice. The plan should be based on the choices and preferences of the individual and be developed with the individual and those persons agreed to by the individual. The interdisciplinary teams that currently plan community services typically start with what exists rather than what individuals may want. They frequently reinforce the image that professionals know best and that the individual, family, and friends have only adjunctive knowledge. While professionals should not be cast aside in a rush for community participation, their role should change. The individuals, with their families and friends, should determine the vision of the future while professionals help in achieving that vision. This shift in roles not only empowers individuals, but maintains the protections now existing in professional support. It also includes the protections that are present when concerned family and friends are involved. It is true that the best protection that any of us have are the family and friends who care about us.

The only effective way to learn what someone wants in life is by listening. We must begin by listening to the words and behavior of the individual, and then we must listen to those who know and care about the individual. The technology by which we gather, organize, and make decisions based on the resulting information is referred to as *person centered planning*.

Because what people want today may not be what they want tomorrow, person centered planning is the ongoing expression of choice by individuals and their families. Agencies involved in person-centered planning recognize that people may request, at any time, a review of their plan by the service provider(s) or the funding/oversight agency.

...it is important to introduce market forces by allowing individuals...to "fire" their service providers, for any reason, and have the funds be available to support the purchase of services from an alternative, qualified provider.

Empowering individuals and their families to review and redesign their plans clearly gives individuals an opportunity to seek redress where choice has not been honored or the individual is at risk. Where families and individuals have divergent opinions about the services, the individual should have the final say.

One of the frequently asked questions regarding supported living is how often the person centered plans

should be brought up to date. The answer is, as often as needed. People's desires and need for change do not occur on an annual or quarterly cycle. People with disabilities should not have to wait for a scheduled review meeting to change who they live with, where they live, or what they do during the day. Service providers have raised a concern about excessive requests; "excessive" requests for reviews are rare and the potential benefit far outweighs the cost.

People with severe disabilities rarely have control over their boundary choices, that is where they live, who to live with, and what to do with their time. This absence of control is the single greatest difference between the lives of people with severe disabilities and those without. To compensate for this it is important to introduce market forces by allowing individuals (or their representatives) to "fire" their service providers, for any reason, and have the funds be available to support the purchase of services from an alternative, qualified provider. Certainly this is the most dramatic change in the typical service structure. It begins to move the individual from "consumer" to "customer." It makes it clear that the people who must be listened to are those with the disabilities (and their representatives). It is based on the premise that people with disabilities (and those closest to them) know what is in their best interests. Because people are living in their own homes, changing who provides the support does not require changing where the individual lives. While real control is only present when an individual can "fire" one provider and "hire" another, typical practice will be different. The power to "fire" will result in the desires and preferences of people being taken seriously.

Simply supporting people in their choices is not enough. Unless creative use is made of the resources of our communities, people will still have lives that are isolated and the costs will increase. Therefore, there is a need to encourage the use of natural supports while assuring that the health and well being of the individual participants are protected by requiring that training be commensurate with duties and responsibilities. Requiring that a paid neighbor go through three days of training before he or she can help you prepare meals is an effective disincentive to the use of natural supports. However, having no training requirements for people who provide limited, specific services, increases the risk of harm or neglect from a lack of knowledge. For example, a neighbor providing supports to someone who has a seizure disorder that is not controlled by medication should have training in what to do when there is a seizure if the neighbor is providing supports when there is no other knowledgeable person present. Requiring that the training be commensurate with duties and responsibilities allows the training to be tailored to the desires and needs of the indi - vidual and increases the pool of available natural supports.

The experiences of the pioneers in providing supported living indicates that the best protection that anyone can have is an active circle of support. It is also clear that a good support circle takes a great deal of time and effort to develop. The monitoring boards required by the CSLA legislation can serve as the quality assurance bridge from which circles of support can be developed. The requirement for a "monitoring board" can be used to establish quality assurance review teams. The composition of these teams must be agreed to by the individual and the service provider. Each individual should be visited at least twice a year by a review team, which determines that: a) the living arrangements and the support plan provide for the health and safety of the individual; and b) that in the opinion of the individual, the individual's representative, and the review team, the services documented in the support plan are being delivered, are having the desired effects, are satisfactory to the individual, and are congruent with the choices and needs of the individual.

CSLA is a pilot effort. Its success will be determined by our ability to break free from traditional "top down" thinking about service provision and quality assurance to conceive a system that responds to one person at a time.

To be effective these activities must be paired with a requirement that service providers respond to any concerns raised by the quality assurance review teams. Providers must indicate what actions they will take, when they will take the actions, and who will carry the actions out. The individuals receiving the services may reject a service provider's response and require that an alternative response be developed. The statutory requirement for a monitoring board initially raised concerns about excessive intrusiveness into the lives of people who were seeking independence. The actual review, with its four questions, is focused away from process and toward outcomes, consumer satisfaction, and the "fit" between the services and the individual.

CSLA is a pilot effort. Its success will be determined by our ability to break free from traditional "top down" thinking about service provision and quality assurance to conceive a system that responds to one person at a time. Success will require the capacity to listen to what people are asking for, help them achieve their desired lifestyles while assuring health and safety, and measure success by focusing on outcomes rather than processes.

*Michael Smull is Director of the Developmental Disabilities Community Support and Access Unit in the School of Medicine, University of Maryland, Baltimore.*

# Quality in Community Residences: Subcommittee Report

*by Robert Gettings*

A panel of the U.S. House Small Business Committee recently reported that a 14 month staff investigation had uncovered "...substantial evidence that patients and taxpayers are frequently being exploited by small businesses that run homes for the mentally retarded and the developmentally disabled." These and other findings were summarized by panel chair Ron Wyden (D-OR) at a March 29, 1993, hearing.

The decision of the Committee's Subcommittee on Regulations, Business Opportunities, and Technology to investigate community residences was triggered by complaints from parents and direct care workers in Oregon and elsewhere. In his opening statement, Rep. Wyden emphasized the seriousness of the findings, noting that while "...most providers appear to be conscientious and professional guardians of some of the nation's most vulnerable citizens," the Subcommittee:

> ...found evidence of retarded or severely disabled persons being raped, beaten and even killed in these facilities. Medicines were misadministered with sometimes disastrous results. The clients had their possessions...stolen, and they were shut-off from family and friends. State public officials charged with their oversight had little or no knowledge of conditions within their homes... or at best found out only after terrible events had occurred.

He also reported that the Subcommittee had uncovered evidence that "...through complex financial organizations, managers of 'non-profit' homes make cash-killing by developing for-profit companies to service these 'shell' facilities through over-priced, sweetheart deals." Operators of community residences, he added, often evade effective oversight because responsible state and local officials lack the resources to perform vital quality assurance functions. Among the other concerns raised by the Subcommittee's investigation were a) inadequate salaries and benefits for direct care workers and resulting high staff turnover and lack of continuity of care; b) "conflicting and confusing jurisdictional problems", especially in monitoring corporations that operate in a number of states; c) lack of a strong federal oversight role; d) lack of adequate competition among providers of community services and resulting difficulties in terminating chronically substandard agencies; and e) absence of appropriate training opportunities for staff.

Rep. Wyden concluded by noting that "we must consider how to build better quality assurance systems." He called for a) improved state standards to protect vulnerable populations; b) a national information system to encourage quality improvements; c) actions to discourage states from over-reliance on any one provider agency; and d) efforts to "beef up" financial auditing of providers.

During the hearing, a mother from Oregon reviewed the many problems her adult son had encountered and said that state officials ignored her repeated requests to intervene. Parents from Michigan indicated that their daughter was raped by the operator of the home and criticized state officials for failing to properly monitor the home and investigate the criminal behavior. The Director of Special Audits for the Massachusetts Auditor's Office testified that "...explosive growth in the [community residential services] industry, spurred by deinstitutionalization, [has] outstripped the Commonwealth's ability to effectively regulate the programmatic content and financial conduct of provider groups." He noted that recent fiscal audits had uncovered $7 million in misappropriated funds by just three provider agencies.

Toni Richardson, Commissioner of the Connecticut Department of Mental Retardation, urged the Subcommittee to place its preliminary findings in the proper perspective. While conceding that state monitoring procedures are not foolproof and can be improved, she pointed out that repeated follow-up studies have confirmed that "people [with developmental disabilities] are better off living and working in the community. Their lives are richer and their choices are wider." Maintaining consistently high quality community residential services, Commissioner Richardson indicated, depends on the following interrelated variables: a) the agencies and personnel who serve people with developmental disabilities must be competent and motivated to provide high quality services; b) people with developmental disabilities must be afforded adequate protection, which requires some level of traditional regulatory surveillance but, more importantly, the continuous involvement of family members and other interested citizens in service planning and delivery; and c) a commitment by the state and other responsible parties to exercise their oversight functions conscientiously and to take swift, decisive actions to correct deficiencies. She added that, "Piling regulatory mandates on top of one another and dispatching state survey teams to inspect programs are clumsy and limited tools for achieving the outcomes we desire."

The Subcommittee's March 29 hearing may be a signal that the rapidly expanding enterprise of serving people with developmental disabilities in community settings is no longer to be exempted from the types of major national exposés that once were confined to large, public institutions. If so, efforts to improve the effectiveness of monitoring systems and community quality enhancement initiatives will take on an even higher priority.

*Robert Gettings is Executive Director of the National Association of State Directors of Developmental Disabilities Services, Inc., Alexandria, Virginia.*

# Quality Enhancement: A Commitment in Pennsylvania

*by Nancy Thaler*

*"...a man's reach should exceed his grasp,*
*Or what's a heaven for?" - Robert Browning*

People with disabilities have the same dreams in life as everyone else. We all want to love and be loved, to find friendship, to win our share of prosperity, to accomplish something that will make a difference, and to be recognized for who we are and what we've done. But everyone needs support to make their dreams come true.

Family and friends are our first line of support. It is natural to seek help first from those who know us best and who share our dreams. From our family and our friends we may receive understanding, advice, a helping hand, and sometimes even money. And sometimes this is enough. But, there are also times when some of us need more. Sometimes we need supports that come from organizations and from strangers.

How can organizations and strangers, providing something we call *formal* services, possibly help anyone to reach their own very personal life dreams? The answer must be that those strangers and organizations must make it their business to find out the hopes and the dreams of each person they attempt to serve. We can only help if we know what our goals are, and our goals are the dreams of each person we serve. The only way to discover those goals, those dreams, is through communication.

The first step is for us to find out from the person we seek to serve what it is that the person wants. The true quality of the formal service being provided, its very justification for existence, will be determined by that person as that person measures his or her dreams. You might say that the quality of service hangs on how much we strangers become friends, on how much we get to know what we need to know to do our jobs, and on how well we come to know the person.

There is a fear that if we try to help everyone reach his or her dream, we will be overwhelmed and paralyzed. It seems too big a task. But, on the contrary, involvement in the fulfillment of a dream is a source of energy. Nothing drives one like a personal commitment. And nothing is as reinforcing as sharing the joy of a dream realized.

Then again, how can we be sure we're doing the right thing? We can only find out by asking. We can ask ourselves, our peers, anyone, even those in authority. But, most of all, we must ask the people we intend to assist.

In Pennsylvania we've made some decisions about who is responsible for quality in the services we provide and about how we are going to go about pursuing quality. We've decided that quality is *everyone's* responsibility. We've decided that an active, vital partnership among people who are caught up in the search for quality is preferable to a well-staffed, administrative contingent whose job is only to put marks on a checklist and to publish reports. We want the right people, the ones who really care, to be on the watch.

Specifically, we expect that in each county in the state a group will form made up of consumers, family members, advocates, providers, governmental staff members, and concerned citizens with the support of the County Office of Mental Health and Mental Retardation. The job of the County Office, with support from the state, is to make sure that this group includes the most interested, the most vocal, the most concerned people. This group - it could be called a quality enhancement committee - will work first to get to know each other as people and then to develop a consensus of shared values and expectations. From this common understanding of purpose and direction will come the impetus to ask the questions that need to be asked: To what extent are generic services available to people with mental retardation? Can we say that the individuals we serve participate as full and equal members of the community? Are consumers and family members involved at all levels of decision-making? Do the services we provide really help people to learn and grow? Are the people for whom we provide services satisfied with those services? Is our work addressing the life dreams of the individual?

The process must be in the form of a loop. We set expectations, we investigate and discover what's really happening, we measure reality against our expectations, and then, to complete the loop, we plan for improvement. And the process goes on.

Some might say there are risks to this approach. We forsake standardization; we give up uniform data collection to demonstrate our achievements. But in trade for standardization, we hope to gain the enthusiasm that local empowerment creates. In place of data collection on compliance, we look for widespread personal involvement. Some may ask, "What will happen to quality if we depend on local initiative?" Well, what chance have we at real quality if our only tool is a checklist wielded by an employee of the state?

Enhancing the quality of the services we provide is a never-ending pursuit. The harder we work to reach some optimal state, the farther it may seem to move away from us. But quality is not something to be grasped once and for all. Rather, it is the art of reaching. It requires tolerance for constant dissatisfaction. Satisfaction is the enemy of quality. We must celebrate our accomplishments only while planning our next moves.

*Nancy Thaler is Deputy Secretary for Mental Retardation, Pennsylvania Department of Public Welfare, Harrisburg.*

# Quality Assurance for Quality of Life in Utah

*by Georgia Baddley*

Ralph is a man with varied interests who shares an apartment with a friend and receives the support he needs to live independently from a Utah provider agency. He has a job landscaping the apartment complex where he lives and is actively pursuing hobbies and interests of his choice. It has been two years since he moved out of a nursing home and into his own apartment, and many changes have occurred in his life.

When Utah's Quality Assurance team first met Ralph he had difficulties with mobility and was slowed down by chronic seizures. These conditions prevented him from attending his sheltered employment setting most days. Today, as a result of focusing providers on quality of life outcomes for Ralph, his seizures are under better control, he is more successful in his job, and he gets around independently using public transportation. Ralph is involved with his family again, makes his own decisions about his daily routine, makes friends wherever he goes, and enjoys visiting old friends and taking them plants that he has grown in his garden. Everyone agrees Ralph's quality of life has significantly improved.

In 1990, the Utah Division of Services for People with Disabilities (DSPD) changed the structure and focus of its quality assurance activities. The change was in response to challenges from the Human Services Research Institute (HSRI) in Boston, and a Legislative task force. A Quality Assurance Academy, whose membership included representatives of all the stakeholders in the state, was established to operationalize a new focus on quality of life.

The Academy proposed that DSPD enhance technical assistance, develop standards emphasizing internal provider quality assurance systems, fade standard compliance monitoring, and develop consumer satisfaction surveys. Three principles were then identified upon which services for people with disabilities in the state of Utah should be based: choice, community membership, and individualization. These principles, along with the guiding DSPD mission "to promote opportunities for persons with disabilities to participate fully in Utah life," were incorporated as the major components of a new DSPD Quality Assurance program. That program includes assessment of provider services on four standards: 1) personal growth and development; 2) consumer participation in his/her own Individual Program Plan; 3) consumer participation in Utah life; and 4) the provider quality assurance program. The focus of the state survey process was changed from paper and process compliance to observing the quality of real world outcomes for individuals receiving services.

Utah's outcome-centered approach involves observing and talking to the individual receiving services and to attendant staff. The person-centered focus of the process requires surveyors to observe for the presence of behavioral indicators of acceptable outcomes and ask questions for clarification. For example, staff wait for the individual to complete a task, even when the person is slow, rather than completing it for them. Also, staff only provide as much assistance as is necessary for success. And, when speaking, staff use a friendly, age-appropriate tone of voice.

Incentives such as awards for superior performance and opportunities to negotiate less frequent surveys have been included in the plan to encourage providers to develop viable quality assurance plans and develop innovative programs. These agreements for less frequent surveying free quality assurance specialists to concentrate their attention on program development.

The first year of implementation was a hold harmless year. At the end of the following year (1992) our data showed that 68% of the surveys had resulted in satisfactory ratings on all four standards. When unsatisfactory assessment required a plan of correction from the provider, technical assistance was offered to the provider from the Division office. Feedback from the providers who had difficulties meeting expectations suggested that some of them did not take the changes in focus seriously and did not make the necessary changes in their agencies. Required plans of correction helped them to focus on what they needed to change and develop a plan for doing so. Providers who had a positive experience with the new survey approach felt that our focusing on outcomes for people instead of paperwork helped them to show off their programs and demonstrate what they do regularly. They became ambassadors for this approach to surveying.

The quality of life has changed for many people in Utah because of this change in focus. The annual consumer satisfaction survey has indicated that the people receiving services, or their families, are satisfied with the services they receive. Positive changes include many examples of people with jobs they like, participating actively in the life of their communities, and pursuing their hobbies and interests. This has happened because someone has made the effort to find out about their individual interests and desires. People have generally become more involved in decision making surrounding their lives. Overall, there is now a sense of people wanting to find new ways of including people with challenging disabilities in Utah life by treating each person as an individual with unique wants and needs.

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# Continuous Quality Improvement in Oregon

*by Darla Wilson, Jimmy Clarke, and Meredith Brodsky*

It is no overstatement to say that Total Quality Management (TQM) is sweeping the United States. References to the need for a transformation in American organizations from top-down autocratic models of management to participatory, quality-driven systems appear in American media every day. Examples of private, for-profit companies in the United States changing their management systems to TQM models include some of the biggest and most successful: Motorola, Ford, and Xerox are but three.

Recently the expectations of customers, taxpayers, and the demands of competition have begun driving many other United States organizations, including not-for-profit and government agencies, towards a TQM approach. In Oregon, for example, 40 top business leaders recently told staff and legislators that they needed to adopt the principles of Total Quality Management to more effectively and continuously meet the needs of Oregon's citizens and taxpayers.

There is often a very large gap between a company's desire and its practical ability to convert to a TQM approach for providing excellence and continuing improvements in goods and services. Many of the words used to describe Total Quality Management sound great - teamwork, continuous improvement, delighting customers - but the fact is that the change takes a lot of work. Large private United States companies have spent millions on quality experts to teach and guide their transformation efforts. Most small companies, especially government-funded and not-for-profit groups, cannot afford such an approach.

With this reality in mind, the Oregon Mental Health Division funded Paradigm Systems to develop a quality process for use in residential and vocational programs that support people with developmental disabilities. The goal was to assist in introducing the benefits of Total Quality Management with a minimum need for outside expertise. The resulting system of continuous quality improvement has been customized in many ways for this type of non-profit, human services organization. For instance, it is sometimes difficult to approach "customer satisfaction" with people who only recently are being asked about their preferences and who may have limited communication skills. For this reason, a multiple perspective approach to quality became very useful.

Many groups of people helped identify characteristics of quality in services for people with developmental disabilities: people with developmental disabilities, their families, staff who work in their programs, members of the community, program managers, and members of a program's board of directors. The characteristics are detailed in a manual of quality indicators that describes a quality assessment and improvement process with four primary steps: 1) forming a management team; 2) gathering survey information; 3) selecting areas for improvement; and 4) forming an improvement team. In Paradigm System's approach, many groups contribute many different types of information about desired characteristics of quality with a program's actual current performance. The specific areas, number of survey items, and respondents of the surveys include: 1) management practices (10 items; board of directors, managers, and key staff); 2) advocates involved in monitoring (30 items; staff self-evaluation, and 3 outside visitors); 3) quality of working conditions (8 items; support staff); 4) consumer quality interviews (12 items; service consumers); 5) family questionnaires (9 items; all families); and 6) staff satisfaction (8 items; all staff). This information can be used in many ways: in identifying issues for strategic planning, as the focus for a structured improvement process, for targeting training activities, and to fuel informal change. Materials present structured activities that can be useful in selecting improvement areas and tackling improvements.

We believe and hope that these systems will effectively allow small organizations to change to gain the benefits of a total quality management approach.

Another real-world adaptation in Paradigm System's Continuous Quality Improvement System is a set of "best practices" that describe areas of different programs that excel in some particular area of service delivery. By sharing information about successful efforts to meet the needs of and delight Oregonians with developmental disabilities, these best practices provide other programs with a type of description benchmark to help with their own improvement efforts.

Like any product that supports quality improvement programs, we actively pursue feedback from our customers about the utility, effectiveness, and usability of our quality improvement concepts, methods, and materials. In addition to the changes we regularly make based on this feedback, we are currently adapting surveys and activities to hospice programs, to programs that provide support to people with mental illness, and to the field of education. We believe and hope that these systems will effectively allow small organizations to change to gain the benefits of a total quality management approach.

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# A Reorientation to Quality Assurance in New York

*by Thomas Cuite*

Can a governmental quality assurance process be devised to encourage providers to focus differently on service provision? Can that process directly address the expressed goals and objectives of consumers and providers, rather than rely on a review of systems and procedures? Can it endorse an organization for its strengths as well as identify its weaknesses? Is it possible for a quality assurance process to focus on specific values without neglecting the essential elements of individual health, safety, and protection? Can it effectively assess providers on their ability to manage, self-evaluate, correct, and achieve positive outcomes? A system being developed in New York is seeking positive responses to these questions. It relies on several factors already existing in many provider organizations, and weaves them into a new monitoring and regulatory process. This system - called COMPASS - is named for its key elements: Consumerism, Outcomes, Management Plans, and Self-Surveys.

COMPASS assumes that most agencies that provide services are well intended and capable of always improving what they do, and that they continue to both aspire to and achieve improvements. It also assumes that the organization can, and will, manage itself well and that it is not necessary for the reviewers to identify routine maintenance and/or operating problems that may exist on a certain day.

The COMPASS system relies on an agency's ability to self-evaluate and manage, and thereby achieve objectives that promote the desired outcomes of people with developmental disabilities. The goals of COMPASS are to (a) streamline the review/regulatory process via one visit to an agency to license all of their programs; (b) encourage consumerism; (c) exempt well operated organizations from detailed third party regulatory review; (d) promote widely valued outcomes and encourage organizations to focus on them; (e) encourage organizations that may not be performing well to improve by adopting these methods; (f) create greater awareness and understanding of regulations; and (g) promote goal-oriented activity for employees. The role of the regulator in COMPASS is to review outcomes in-depth and, when satisfied, cursorily verify that the agency has an active and thorough process to be responsive to consumer input, that it has a management plan of its own design that enables continuing quality improvement, and that its employees conduct a self-review, including a review of regulatory compliance and an assessment of the agency's progress. A satisfactory in-depth review of outcomes and minimum verification that the agency has engaged in a quality management program will result in continued licensing.

The COMPASS model is being tested by 24 agencies in the state for 12 months, with an evaluation to be completed by September, 1994. The demonstration period will enable all concerned to determine whether a sound recertification decision can be made based upon a review of outcomes, and what the impact of this model will be for provider organizations with unique characteristics and differing operating philosophies.

The outcomes promoted by COMPASS - independence, inclusion, individualization, and productivity - are embodied in the objectives of many state programs, many provider and consumer organizations, and federal and state program requirements. They are identified as components of quality of life in the research literature and valued outcomes reforms in several other states. It is the definition and assessment of these outcomes that is the key and most difficult element of linking the operating and regulatory environments. COMPASS has been able to draw on the definition and assessment approaches developed, evaluated, and tested in other states. As a result of combining these elements in a self-monitoring and review process, COMPASS will permit both providers and reviewers to focus on the larger and longer term objectives valued by consumers and maintain the successful systems and procedures needed to achieve the outcomes.

Too often, passing the regulatory test becomes the sole objective of an organization, and its employees lose sight of the purpose of a specific regulatory requirement. Such orientation actually impedes improvements, keeping organizations at or near the minimum level of regulatory compliance. COMPASS provides an incentive for organizations to think and behave differently. It is not intended to be instituted in agencies that seek only to pass a regulatory review and do no more than required by the letter of the law or regulation. It can only work with agencies that are committed to and capable of working to achieve the identified valued outcomes, and willing to view the quality assurance process as an opportunity to assist them in improving.

COMPASS is a new attempt to integrate the benefits of regulatory certification activities with a mechanism that reflects how an organization operates and enhances the quality of its services. The result should be an enhanced quality of life for the individuals served by the participating provider organizations.

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# Service Enhancement Through Self-Examination in Connecticut

*by Joseph Harrison-Becker and Dennis Mitchell*

What are the opportunities created by a service that fosters respect and dignity, fulfilling relationships, choice, personal competence, and presence and participation in life for individuals with disabilities? How satisfied with the offered support are the persons receiving service and their associates? How might providers of service change their actions to improve individuals' quality of life? Self-examination, based on values, is the route to answering these questions during the Service Quality Review Process (SQRP) and Values Explorations Workshops (VEW) facilitated by the Service Enhancement Unit, Connecticut Department of Mental Retardation.

The SQRP and VEW activities are aimed at helping day and home providers of service improve the quality of support they give to persons with disabilities, and therefore improve the quality of life for those individuals. Service enhancement participation is voluntary. Providers of service select or create the kind of enhancement activity they wish to participate in be it VEW, SQRP, or a different negotiated activity.

VEW, a 20-hour values exploration event with 10 to 30 participants, assists people in examining their beliefs and values about individuals with disabilities and the service practices that support them. Participants in VEW include those receiving services, friends and relatives of people receiving services, interested community members, direct service staff, and managers of service organizations. VEW, an open participatory forum, includes:

- Discussion of values, their meaning and importance, and how values relate to real life situations and experiences for persons with disabilities (e.g., What are respect and dignity? Why are respect and dignity important? Tell me about the experiences in services that relate to respect and dignity?).
- Wall charting of participants' comments throughout the discussion. Participants "see" what they think and reflect on everyone's ideas during discussion. After the VEW, these comments are typed and sent to all participants.

SQRP is an opportunity for providers and others to do the following:

- Examine actions of a service and the beliefs held by those associated with providing service in the light of values (assessment phase).
- Develop enhancement actions to take (brainstorming, planning phase).
- Carry out actions based on values in support of persons receiving services (change phase).

SQRP is voluntary and requires permission by providers of service and service participants to occur, with all information maintained confidentially. Specific components of SQRP include:

- A team, often including persons with disabilities and interested community people, conducts the review. Team behavior and sensitivity to participants' dignity when visiting the service is negotiated prior to the review.
- Team members, visiting the service site, listen to persons receiving services, their relatives, friends, advocates, guardians, staff, and others and observe what is going on within the site.
- Team members write about what they see and hear, and reflect on values as they apply to given service situations. The story is further fleshed out by people associated with the service.
- Service providers and others ponder the story, brainstorm service changes based on values, and plan and implement enhancement actions.

The Service Enhancement Unit continually examines its own actions to see if what it does is in accord with the values it seeks to instill and/or sustain in others. Just as it is important for service providers to continually explore changes that will benefit consumers, the Unit continually changes what it does. The goal of our changing is to build more trusting relationships, and expand the level of participation and choices for providers of service as they seek to improve the quality of life for persons with disabilities.

Participants have said the VEW has directly affected the lives of people who receive support. For example, one home manager said she met with staff and began discussions of values; as a result, staff have altered how they support individuals. Outcomes of the SQRP have included increased contact among persons and their relatives, more decision making at home and in the community, and individuals making more money as a result of their participation in performance studies. Opportunities for life-fulfilling experience are a result of self-examination.

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# Performance Contracting for Service Quality in Minnesota

*by Robert Meyer*

In 1971, the Intermediate Care Facility for the Mentally Retarded (ICF/MR) program was established under Medicaid. Its primary goal was to upgrade large institutions by providing federal cost-sharing for care in facilities meeting federal standards. Because of federal cost-sharing, many states certified community group homes as ICFs/MR. Minnesota led the way; by 1982 its 2412 residents in smaller, community ICFs/MR were 25% of the national total. Since 1982, Minnesota's community ICF/MR population has remained virtually unchanged as the state has focused on Medicaid waiver and state/local financed community services. A major advantage of this focus has been freedom from the ICF/MR standards' lack of flexibility, focus on process and record review, regulatory burden, limited relationship to people's quality of life and personal preferences, and the associated human and dollar costs.

As part of a series of reforms in developmental disabilities services, the Minnesota Legislature has authorized demonstration projects to improve ICF/MR services by focusing on the achievement of specific consumer outcomes. Payment for services will be based on a contract for achievement of outcomes rather than extensive cost reporting and documentation of compliance with process standards. Demonstrations are expected to last four to five years with the potential of adding programs over time. It is anticipated that the demonstration projects will: 1) provide increased choices for consumers; 2) increase consumer satisfaction with the services; and 3) achieve the lifestyle and personal development desired by consumers.

Providers will be selected to participate in this demonstration through a request for proposal process. Selection criteria will include the provider's: 1) commitment to providing high quality services; 2) past performance in complying with licensure and certification standards; 3) ability to develop creative alternatives to existing regulatory approaches in achieving service quality; 4) financial stability; 5) cost effectiveness; and 6) establishment of local service networking and cooperation among agencies.

The performance contracts and associated outcome indicators will be required to include attention to: 1) personal health, safety, and comfort; 2) personal growth, independence, and productivity; 3) client choice and control over daily life decisions; 4) client, family, and case manager's satisfaction with services; and 5) community inclusion, social relationships, and fulfilling valued community roles. Other areas may be established by an advisory group. Minimal assurances and procedures will be required to assure that health and safety will not be compromised.

Additional program flexibility will be required from the federal government to allow waivers of ICF-MR regulations or their interpretations. For example, specific individual outcomes, related performances of the provider, and a protocol for their assessment will need to replace universal standards for active treatment in the demonstration.

Extensive training and technical assistance of consumers, families, providers, and county and state agency staff will be conducted to implement the demonstration projects, with additional administrative resources requested. Participating service providers will also be expected to allocate additional dollars for training staff and consumers.

Review of the documented outcomes for individuals will be conducted annually by their case managers and legal representatives. Monitoring of service quality will also be done by family members and other trained volunteers. Individual outcome evaluations will include: 1) achievement of client outcomes and performances; 2) client, family, and case manager satisfaction with services and supports; and 3) recommendations for improving the services.

Each provider will be expected to implement systems of self evaluation and continuous quality improvement, including surveys and interviews with consumers, staff, board members, advocates, and county personnel; other methods of feedback; and training and technical assistance to ensure improvement of service quality. The whole project will be evaluated over several years, examining: 1) effects of performance contracting on quality of life; 2) cost and service effectiveness; 3) determination of performance indicators most predictive of broad outcomes desired; and 4) recommendations regarding statewide implementation. The University of Minnesota will be involved in the design and implementation of this evaluation.

We believe this demonstration will lead to seven important outcomes: 1) increased influence of consumers and families in the development, monitoring, and improvement of services; 2) service quality measured in terms of desired outcomes for the consumer, with outcomes forming the basis for service improvement; 3) development of a single set of consumer outcome indicators for systemwide evaluation and improvement of services; 4) increased direct responsibility for providers to improve services and implement quality management efforts; 5) increased state focus on technical assistance and support; 6) establishment of local service networks to provide broader arrays of choices and increased service effectiveness, coordination and efficiency; and 7) determination of effective methods to secure, evaluate, and pay for desired consumer outcomes.

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# Consumer Monitoring of Services in Oklahoma

*by Dennis Bean and John Gajda*

Choice and empowerment have rightfully emerged as central components of many human service systems providing supports to individuals with developmental disabilities and their families. Oklahoma's efforts to embrace and implement these concepts have included the development of a consumer monitoring program. The program provides individuals served and their families an opportunity to evaluate providers of services, impact the quality and responsiveness of services, and exercise informed choice. This program is called Oklahoma Advocates Involved in Monitoring (OK-Aim), and it is coordinated by the Tulsa Association for Retarded Citizens.

OK-Aim was born in 1990 when the state's recent commitment to aggressive expansion of community alternatives presented challenges to consumers with regard to their exercise of choice. In three years the number of community support providers grew from 40 to 103. At the same time the array of supports grew significantly to include not only small and medium size group home services, but an array of in-home supports. While choice was considered an essential component of the state's service system, the integrity of choice was compromised by the difficulties individuals and families experienced in obtaining information that would allow them to distinguish among various providers or support types. It was also evident that while existing Quality Assurance provided minimal standards for services, these mechanisms were unable to adequately assess or influence the subjective elements of service delivery that truly define quality. Survey processes resulting in licensure simply could not speak to the presence or absence of comradeship, mutual respect, and other human aspects of environments.

To change this, a group of consumers and family members spent a year and a half reviewing consumer evaluation activities in other states, borrowing many concepts, and refining and inventing others. One of the first products of this effort was the following set of guiding principles that served as a focus for the development of OK-Aim:

- People with developmental disabilities are people first.
- All people are entitled to the same privileges and responsibilities.
- Services should provide the assistance needed to allow people to be full members of their communities.
- Consumers should be able to choose the providers of services they receive.
- Consumers should evaluate the effectiveness and appropriateness of the services they receive.
- The opinion of the primary consumer shall be given the most important consideration in evaluating service provider agencies.
- By making informed choices based on information describing a service provider agency's performance, consumers will influence the quality and responsiveness of the services.

The group also developed 36 expectations considered essential elements of quality services. For each expectation guidelines were designed to clarify attributes of excellence as well as circumstances considered unacceptable.

Through OK-Aim, consumers volunteer to visit the homes of individuals receiving residential supports funded through the state. The focus of each visit is to understand relationships within the home, explore opportunities for relationships with neighbors, support inclusion in the community at large, and gain a general impression of the home's cleanliness and safety. At the conclusion of each visit, volunteers share their impressions and reach consensus on each of the 36 service expectations. Their conclusions are synthesized into a written report, which frequently includes recommendations for service enhancement. The report is shared with the provider, who may respond with the knowledge that the responses will be incorporated in the document. The final report is made available to consumers.

Nearly 100 individuals are currently serving as OK-Aim monitors. Approximately 55 are parents or otherwise related to individuals served, and nearly 40 are primary consumers of services. The remaining individuals are citizens who participate in surveys of larger facilities.

The State has been pleased that providers have widely embraced the program. OK-Aim visits do not have the aura of regulatory surveys. The interactions of volunteers have proven productive not only in the development of general recommendations for service enhancement, but in the provision of on-site practical technical assistance by volunteers. In addition, site visits have resulted in the development of many meaningful personal relationships between OK-Aim volunteers and individuals served. In summary, OK-Aim has demonstrated the capacity for successful working relationships between state funding agencies, advocacy groups, consumers, and providers to achieve mutually desired outcomes defined by individuals served and their families.

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# Gathering Quality-Relevant Data in Colorado

*by Judy Ruth and Lynne Struxness*

Considerable attention is currently being given to improving the quality-relevance of data gathered about individual agencies and settings serving persons with developmental disabilities. State agencies with administrative, policymaking, and resource allocating responsibilities have a need for quality relevant information about the services for which they are responsible on a system-wide basis. This need is being addressed in Colorado through a series of studies using an instrument entitled *COPAR, Colorado Progress Assessment Review*.

The Colorado Division for Developmental Disabilities has undertaken a series of longitudinal studies of persons with developmental disabilities who are receiving supports from the Division. The purpose of these studies is to determine whether progress is being made towards the Division's mission to provide these persons with a better quality of life, which includes community inclusion, choice-making, self-determination, relationships, exercise of competencies and talents, personal security and self-respect. These studies use the *COPAR* questionnaire.

One area being examined using the *COPAR* questionnaire is community inclusion. The instrument measures participation in 50 activities that are typical for most persons in our society, such as shopping for groceries, dining out, going to movies, and visiting with friends. Results from longitudinal studies in Colorado have documented that persons receiving supports in smaller community settings (apartments and group homes) are participating in more activities than are persons in larger institutional settings. This provides support to Colorado's ongoing deinstitutionalization efforts. Analysis of variance has shown that the differences observed between activity levels of persons residing in community and institutional settings was not attributable to differences in adaptive skill levels of those individuals, but rather due to differences in opportunities. These studies have also identified which support models provide persons with higher activity levels. However, the studies could not tell us if persons in these support models were participating in activities at a level similar to other citizens in Colorado. Therefore, the *COPAR* tool has been applied to a random sample of 1000 persons in Colorado; the results of this study (not yet available), will provide a baseline for determining whether we are providing persons with disabilities opportunities similar to those enjoyed by other citizens of our state, and if not, where to focus attention.

The *COPAR* questionnaire also measures the degree to which a person is involved in making decisions about his or her own life. For example, it examines involvement in choosing clothing, jobs, roommates, support staff, and how personal money is spent. It also looks at whether decisions are made independently, jointly with others, or are made for the person. While we found many positive results, there were also many areas of concern identified through these studies. For instance, the majority of persons in supports have no involvement in decisions concerning their job (or day service), the place where they live, support staff, and grocery selection. Encouraging results included significantly higher levels of choice for persons in community settings than those in institutional settings (even with functioning levels taken into account) and the finding that the majority of persons were independently making many decisions.

One of the goals of the Division is to ensure that persons in services are satisfied with the supports they receive and that they are given opportunities to express their concerns. During the *COPAR* surveys, persons receiving supports are interviewed regarding their satisfaction with services and life conditions. These surveys serve to answer such questions as: Are persons in certain support models more satisfied with their services than others? Are satisfaction levels improving over time? Do satisfaction levels vary by geographical service area, age, gender, ethnic status, or other factors? What would persons like to change about their homes, work or other life situations? While most expressed satisfaction with services, they also indicated changes they would like to see. The most frequently expressed concern was loneliness and a desire for more friends, followed by requests to move (most frequent for persons in institutional settings), the desire for a different job or work duties, and more involvement in decision-making. These responses provide Colorado with an indication of where to put efforts to benefit the most persons.

The *COPAR* surveys provide Colorado with information that assists the State to determine if we are making progress towards our mission. It allows us to evaluate the relative effectiveness of various support models; recognize exemplary programs and identify programs requiring technical assistance; demonstrate to funding authorities the positive difference resulting from expenditure of public funds; determine if individuals being served are satisfied with services; raise the awareness level of those surveyed regarding support outcomes related to the Division's mission; and collect information on special target areas each year. Outcome data is critical to monitor the progress of individual agencies and service settings in meeting contemporary standards for service quality.

*Judy Ruth is Section Chief for Data Management and Lynne Struxness is Research Analyst, both with the Colorado Division for Developmental Disabilities, Denver.*

# Quality Through Direct Service Training in Kansas

*by Kathleen Olson*

Adults with disabilities often receive assistance and support from paid nonprofessional staff. As we move from providing services in congregate settings to providing support in individualized settings, there is an accompanying shift in the responsibilities of these staff. The shift involves moving from roles of basic caregivers to roles of promoting and supporting independence, integration, productivity, and empowerment. Furthermore, in carrying out these expanded roles, direct service staff in individualized settings are working with less professional supervision. A concerted effort to train staff for these new roles and responsibilities is needed if individuals with disabilities are to achieve and maintain an acceptable quality of life.

The Kansas University Affiliated Program (KUAP) is addressing the need for direct service staff training through a statewide training network. This network links resources from agencies across Kansas, including the Kansas Mental Health and Retardation Services (MH&RS), Kansas Association of Rehabilitation Facilities, community mental retardation centers, community colleges, and the KUAP. By combining fiscal and human resources this network has addressed three frequently encountered training challenges: curriculum, relevance, and funding.

The first of these challenges is identifying what to teach and accessing state-of-the-art training resources. This is often difficult, particularly in rural areas geographically separated from universities. With a training grant from the Administration on Developmental Disabilities, the KUAP developed *An Introduction to Developmental Disabilities*, a 116-hour competency-based and value-based curriculum providing an introduction to critical issues in delivering services to people with developmental disabilities. Areas addressed include values, person-centered assessment and planning, communication, teaching strategies, positive behavior change, and health. The curriculum objectives were developed in consultation with the project advisory board consisting of representatives from key agencies in Kansas. The curriculum is structured so it can be taught by persons with moderate levels of expertise in topical areas and with limited classroom teaching experience.

A second training challenge is the practical problem of transferring knowledge and skills from the classroom to the work setting. To be relevant, training should be understandable and have practical application to the real-life work situations of direct service staff. The practicum component of our curriculum requires direct application of classroom concepts. On-line supervisors oversee practica, encouraging discussion and providing further support for new ideas.

Finally, it is always a challenge to obtain resources for direct service staff training because adequate funds are rarely earmarked for it. In Kansas, the MH&RS has funded trainers to teach this curriculum in community agencies. Currently this curriculum is being taught by 32 of the 38 community agencies. With curriculum and funding available, local agencies are able to tailor the materials to meet individual agency needs and to efficiently use staff time and materials. The use of a common curriculum has enabled some agencies to share teaching responsibilities by co-teaching or opening up classes to staff from neighboring agencies, thus easing the demands of staff scheduling for any one agency. Supplementing resources further, community colleges provide salary and technical assistance to instructors. By teaching through community colleges, some staff have also been able to obtain college credit at tuition-reduced rates.

While instruction through colleges is encouraged, Kansas has chosen not to create a new degree program directed primarily at career ladder movement to supervisory and management positions. As we move from program-centered to person-centered approaches, the need for tiered levels of management should decrease. While professionals are clearly needed to provide special services in some areas, the greater need is for training in the values and techniques that enable staff to provide individualized transdisciplinary support. We do not view specific career objectives and formal degrees as a critical component of ensuring quality services. We continue to rethink the extent to which we want to redirect our training efforts from caregiving or management to value-based training aimed at providing staff with the skills to empower persons with disabilities. We also recognize that there is a need to provide ongoing training for direct service staff who remain in their current positions.

Although in the early stages, this approach to training direct service staff shows promise in promoting quality services on systemic, agency, and staff-consumer levels. On a systemic level, it has required interagency communication in identifying common goals and objectives, and in combining resources to reduce duplication of efforts. It is clear that the interface of resources across agencies increases the scope and strength of the training activities of each. With the large number of agencies involved, face-to-face interaction of trainers from different agencies facilitates sharing best practices. Within agencies this approach assists communication across levels of staff, solidifies agency policy, and focuses service delivery. Increased awareness of the values of service delivery assists direct service staff to focus on and refine their roles in supporting and empowering persons with disabilities, thereby enhancing service quality.

*Kathleen Olson is Coordinator of Kansans Educating and Empowering Persons with Developmental Disabilities, KUAP, Parsons.*

# Improving Quality Through Parent and Self-Advocate Training

*by Colleen Wieck and Thomas J. Zirpoli*

Service delivery systems frequently place persons with disabilities and their families in passive roles with few opportunities to express their needs, review alternatives, and make decisions regarding their own futures. At the very least, these systems have decreased the significance of the family's role as primary provider in the life of their children, and the consumer's role as the primary decision maker regarding their needs. While self-advocacy may not be possible for everyone, and should not be a requirement for families to receive appropriate services, self-advocacy education programs are being organized throughout the nation. Partners in Policymaking has served as a national model for family advocacy and empowerment training since 1987.

Partners in Policymaking is an on-going, federally funded grant program under the direction of Minnesota's Governor's Planning Council on Developmental Disabilities (GPCDD). The program is designed to provide information, training, resources, and skill building in the area of developmental disabilities to families of young children with disabilities and to consumers with disabilities. The program's goals include educating and empowering people so that they may obtain the best available services.

Program participants are asked to attend eight two-day training sessions for a total of sixteen days of leadership and self-advocacy training conducted over an eight month period. Training sessions begin on Fridays, shortly after the noon hour, and conclude on Saturdays. Speakers have included national experts in developmental disabilities; local, state and national legislators; and representatives from advocacy organizations. Session topics include an overview of the history of the parent movement and independent living movement; community organizing skills; state legislative issues; integration and quality education; severe physical disabilities and technologies; county planning and budgeting; case management; supported employment, supported living, and family supports; and strategies for effective meetings. Examples of skills that are integrated throughout the sessions include successful techniques for advocating for services, meeting with and providing testimony to public officials, and whole life planning.

A maximum number of 35 people have been selected to participate in the Partners program each year. Participants are selected by a committee consisting of representatives from the GPCDD and the community (including parents of children with disabilities and individuals with disabilities). In an effort to assist and encourage participation regardless of economic status, related travel, meals, lodging, respite care, and child care expenses are paid from grant funds.

Evaluation of the Partners program by participants has been overwhelmingly positive. The evaluation of Partners has three primary components: participant evaluation of each training session using a Likert scale of 1 (Poor) through 5 (Excellent); completion of a comprehensive evaluation of the overall program; and longterm follow-up survey data collected from all participants who are again asked to evaluate the program and provide information regarding their own advocacy activities since graduation.

To date, overall program evaluation and longterm follow-up data have been returned by 130 of the 163 graduates from the first five years of the program. Results include the following:

- Sixty-seven percent of the participants rated the program overall as "Excellent," and 26% "Very Good."
- Fifty-seven percent rated the program as "Excellent" in teaching them to become a better advocate, and 31% rated it "Very Good."
- Sixty-two percent responded "Definitely Yes" when asked if they had secured better services as a result of their participation in the program; 31% said, "Yes, Somewhat."
- The majority of participants stated that since graduating they had been in contact with national (62%), state (81%), and local (84%) public officials regarding their individual or family needs. Thirty-three percent had testified at a public hearing, 66% had made at least one presentation to a parent group, 43% had made at least one presentation at a national or state conference, and 73% were serving on a committee or commission on disability issues.

In addition, many participants have developed support networks and friendships through the program, and some indicate that they now experience greater confidence, self-esteem, and ability to create changes in the system.

The GPCDD has secured federal grants from the U.S. Department of Health and Human Services to assist other states in establishing Partners in Policymaking programs. During the past three years the GPCDD, in collaboration with several other national and state organizations, has conducted training academies about the Partners program for representatives from other states. Many of these representatives have since initiated similar programs.

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# Parent Case Management Training Promotes Quality

*by Marijo McBride*

In the past, the management of services for persons with disabilities was largely left to "professionals." Today, more and more families and individuals with disabilities want to be involved in identifying their own capacities, needs, goals and supports, which ultimately enhances the quality of the services and supports that they receive. Parents and adults with disabilities are increasingly viewed as professionals working in partnership with other professionals. Minnesota's Parent Case Management Program has succeeded in empowering participants to take the leadership role in case management for themselves or their child by offering training, ongoing support, and technical assistance.

The Parent Case Management Program was established in 1986. Funded by the Minnesota Governor's Planning Council on Developmental Disabilities, the program is based at the University of Minnesota's Institute on Community Integration. The program began by training parents/guardians of persons with developmental disabilities and adults with developmental disabilities to take leadership roles in obtaining and monitoring the quality of services they receive. In 1992, the program expanded by implementing a train-the-trainer model. Today, in addition to training individuals to manage the services they receive, the program trains parents, persons with disabilities, and other interested community members to fill the role of program facilitators throughout the state. These facilitators return to their communities and implement the program.

Through training, support, and follow-up, the program enables participants to develop knowledge and practice skills in the following areas:

- Case management procedures, responsibilities, and strategies.
- Civil rights of persons with developmental disabilities.
- Data privacy and record maintenance.
- State of the art service provision.
- Quality indicators.
- Inclusion.
- Effective use of resources.
- Case management rules /regulations.
- Transition planning/implementation.
- Identification of needs, goals, services and resources.

The program has trained 90 parents and adults with disabilities to take the leadership role in case management for the services they receive. Eighty-one percent of recent parent case management graduates report that as a result of the training they are able to more effectively participate in case management for themselves or their children with developmental disabilities. An additional 32 individuals have been trained in the past year to fill the role of facilitators in their communities, and are now offering training across the state. An additional measure of the program's success is its replication: the parent case management concept is being implemented in eight Minnesota counties through a Minnesota Department of Education grant (see box below).

*Marijo McBride is Coordinator of the Parent Case Management Project, Institute on Community Integration, University of Minnesota, Minneapolis.*

## Parents Help Parents Obtain Quality Services

In our north central Minnesota school district, we found that families who have children with special needs were consistently feeling isolated and powerless. They lacked the necessary information and skills to fully participate in obtaining services. Systems often were unfriendly and difficult to access. Because of these issues and concerns, grant funding was obtained to establish the Parent Partnership Project.

The project's primary purpose is to develop a system by which families of children with disabilities are provided with consistent and accurate information regarding federal, state, and local agency services; family support options; and families' rights to access and use available services. What makes this program unique is the method by which this is accomplished.

With the exception of the grant manager, all staff, including the regional parent facilitator, are local parents of children with special needs working within their own communities. The project provides ongoing family follow-up, which is viewed as critical by the families. In addition, the project provides a method of information dissemination that is adaptable to the unique functioning and individual differences of each participating county service system.

The intent of the project is to build on parent empowerment through use of personal, informative, supportive one-to-one relationships between the parent and parent facilitator. Utilization of parents helping parents provides participants with emotional support and understanding from others who "walk the walk" and "talk the talk" of parents who have children with special needs.

*Contributed by Diane Roth, Regional Parent Facilitator, and Kathy Gaffney, Project Manager, Parent Partnership Project, Paul Bunyan Special Education District, Brainerd, Minnesota.*

# Action Learning for Quality Improvement

*by John O'Brien and Connie Lyle O'Brien*

Today, more than ever before, people with developmental disabilities rely on the capacity for rapid and fundamental learning by the people who serve them. New understandings about people with disabilities, new approaches to support, and new community opportunities and experiences create enduring gaps between common practice and best practice. As long as there is more to learn about creating opportunities for people with disabilities, quality improvement efforts don't stop with the attainment of a stable state. Instead, quality derives from the agency's ability to promote learning through collaborative efforts among people with disabilities and their families and friends, community members, and agency staff.

Because this cycle of learning begins and ends with new understandings about people with disabilities as community members, agencies regularly meet the challenge of learning to do significantly different things rather than periodically redesigning stable processes. Within the past seven years, agencies offering day services have had to decide how much to invest in supported employment; agencies that adopted group approaches to supported employment have had to decide how much to reinvest in support to individual jobs; agencies that deployed individual job coaches have had to decide how to reorganize to increase coworker support; and agencies committed to maximizing natural support have had to rethink their approach to job development and support in order to increase employer ownership of the entire process of including workers with significant disabilities. At each decision point, agencies face changes not only in how, when, and where their staff work, but more fundamentally in the work their staff are doing and the reasons they are doing it.

Since 1985, Responsive Systems Associates has been developing collaborative approaches to quality improvement. We have worked with almost 100 groups of people on a series of intensive action learning workshops called Framework for Accomplishment. Our shared goal is to develop processes and concepts useful in reconceptualizing and redesigning services that honor the distinctive contributions of people with disabilities, their family members and friends, service workers, and other community members. Our process is conversational: instead of assuming that outsiders gain a privileged view of truth by applying checklists of quality indicators, we assume that outsiders can contribute to quality improvement by gathering different perspectives, and then creating, sharing, and testing narrative accounts that communicate the quality gap between current reality and a desirable future. Our method is to invite people with disabilities, their families, friends, and service workers to collaborate with self-managed teams whose tasks include: 1) creating an individual profile of each person's current experiences and desired future, and determining what is most important now for each person; 2) describing current service practices from each person's point of view and identifying key capacities the agency needs to develop in order to be of better assistance to the people they support; and 3) identifying constructive actions that make creative use of personal and agency resources in each individual situation.

This action learning approach contributes to organizational learning by creating time and space for reflection and creative problem solving. Beginning with descriptions of people's current experiences, current understandings of desirable futures, and current supports, the process increases awareness of the quality gap by suggesting different ways to think about and use available resources to better serve the person. Continuing refinement of this approach suggests several elements of use in the design of quality assurance, including:

- Include people with disabilities and their families and friends as full collaborators in the process. A person's ability with language or behavioral challenges seem to make much less difference to the quality of participation than the respect with which they are invited into the process and with which they are treated within it.
- Strengthen the voices of direct service staff. Many have untapped good ideas and problem solving skills that will not emerge if a quality improvement process assumes that they are ignorant and untrustworthy.
- Make people accountable for clear judgments about the quality of current experience and options for improvement.
- Clarify the purpose of the work being done. The program asks people to explore three purposes for services to people who require long term assistance: 1) actively help people discover and move toward a desirable personal future; 2) offer necessary assistance in ways that support positive experiences of community memberships; and 3) challenge and build the competence of community settings.
- Challenge agency staff to improve their abilities to listen to people with disabilities, develop community opportunities, assist people to make and keep positive community connections, and be a safeguard for people in difficult times.

Like any approach that constructs a temporary social system to accelerate learning, the effectiveness of the Framework process depends on people's abilities to move its lessons from the stage of reflection into action. This has proven particularly difficult when closing the quality gap calls on agencies to transform the ways they work and are managed.

*John and Connie Lyle O'Brien are Responsive Systems Associates, Litvonia, Georgia.*

# Resources

- **Outcome-Based Performance Measures.** (1993) By the Accreditation Council on Services for People with Disabilities. A manual listing the 30 outcomes identified by people with disabilities that form the basis for the Accreditation Council's quality enhancement and accreditation program. Available from the Accreditation Council on Services for People with Disabilities, 8100 Professional Place, Suite 204, Landover, MD 20785-2225 • (301) 459-2225.

- **Quality Assurance for Individuals with Developmental Disabilities: It's Everybody's Business.** (1990) By V. Bradley and H. Bersani, Jr. Published by Paul H. Brookes, Baltimore. A book in which over two dozen writers discuss quality assurance for persons with developmental disabilities from the perspectives of consumers, families, advocates, government, and others.

- **Continuous Quality Improvement in Oregon's Programs for People with Developmental Disabilities.** (1992) By M. Brodsky and D. Wilson. A publication describing the application of continuous quality improvement approaches to programs for persons with developmental disabilities in Oregon. Available from Paradigm Systems, P.O. Box 967, Salem, OR 97308-0967 • (503) 363-8609.

- **Standards Manual for Organizations Serving People with Disabilities.** (1990) By the Commission on Accreditation of Rehabilitation Facilities. A manual containing standards to assist provider agencies to plan and develop services, train staff, evaluate and improve programs, and prepare for a survey leading to voluntary accreditation. Available from the Commission on Accreditation of Rehabilitation Facilities, 101 North Wilmot Road, Suite 500, Tucson AZ 85711 • (602) 748-1212.

- **Quality is Free: The Art of Making Quality Certain.** (1980) By P. Crosby. Published by Penguin Books USA, New York. A book discussing managing quality in ways that are practical, productive and profitable.

- **Down Stairs That Are Never Our Own: Supporting People with Developmental Disabilities in Their Own Home.** (1991) By J. O'Brien. A publication addressing the significance of choosing and controlling one's home environment from the perspective of persons with developmental disabilities. Available from the National Association of State Directors of Developmental Disabilities Services, Inc., 113 Oronoco Street, Alexandria, VA 22314 • (703) 683-4202.

- **A Summary of States' Efforts to Positively Affect the Quality of Medicaid Home and Community-Based Services for Persons with Mental Retardation and Related Conditions** (Report #34). (1991) By R. Prouty and K. Lakin. A report describing findings of a national survey of efforts by states to assure and enhance service quality for persons with mental retardation and related conditions. Available from the Publications Office, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455 • (612) 624-4512.

- **Supported Living: New Directions in Services to People with Developmental Disabilities.** (1990) By G. Smith. A publication reporting and analyzing emerging trends in supported living for persons with developmental disabilities. Available from the National Association of State Directors of Developmental Disabilities Services, Inc., 113 Oronoco Street, Alexandria, VA 22314 • (703) 683-4202.

- **Supporting People with Severe Reputations in the Community.** By M. Smull and S. Harrison. (1992) A handbook discussing, with practical examples, how people receive severe reputations, how to plan with the individual for community services, how to recruit and develop the supports needed to implement the plan and how to avoid the most common abuses and perversions in providing supports. Available from the National Association of State Directors of Developmental Disabilities Services, Inc., 113 Oronoco Street, Alexandria, VA 22314 • (703) 683-4202.

- **An Introduction to Developmental Disabilities.** (1993) A 116-hour competency-based and value-based curriculum for direct service staff. Available from Kathleen Olson, KUAP at Parsons, Box 738, Parsons, KS 67357 • (316) 421-6550.

## New in Summer 1993 . . .

- **Reinventing Quality: Improving Services for Persons with Mental Retardation and Related Conditions.** (1993) By E. Blake, T. Mangan, B. Prouty, and K.C. Lakin. A sourcebook describing over 50 innovative programs to assure and enhance service quality for persons with developmental disabilities. Available from Publications Office, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455 • (612) 624-4512.

*Redesign, continued from page 1*

## ■ Articulating the Value Base

The first task in redesigning quality assurance is to define quality. Philip Crosby, in his book, *Quality is Free: The Art of Making Quality Certain*, tells us that quality is "conformance to requirements; it is precisely measurable." I used to think that definition made sense in manufacturing because General Motors could make cars conforming to its standards. The problem was that not enough people wanted the cars. There is obviously a dimension to quality that applies to manufacturing and even more so to the human service field, which is that quality is what the customer wants. Building a Cadillac that General Motors thinks is a quality car is irrelevant unless the customer is willing to pay for it.

So if an essential component of quality is meeting the customer's expectations, who is the customer? In the service system as it has existed to date, the customer primarily has been the government agency that certifies, operates or funds the service system. Providers have had to satisfy the regulators and funders, not the people they serve. And government decisions about whether to continue funding and operating programs have depended not just on compliance with standards, but on a host of other considerations, such as the effect of regulatory actions on labor unions and the workforce, alternatives that may be available to meet the needs of current program participants, the economic impact of the program in the community, and the political interests that a provider could bring to bear. However, when agencies write mission statements and policy documents, it is not uncommon to see such documents espouse lofty ideals such as "empowerment," "individual choice," and "inclusion," and remain virtually silent about these political and self-interest forces that in reality shape much of the decision-making.

A significant challenge that must be confronted on this journey to a new world of person-centered, preference-driven service/support systems is answering the following questions: (a) how can people be empowered unless they have effective control over the money being spent on their support, and can choose to spend it differently; (b) how do we truly make the person with a disability the customer whose expectations must be met as an essential component of quality; and (c) how does the current provider-driven system, with its need for predictable budgets and revenues, accommodate to a world where the negotiations will occur not with a single state official for "beds" and "slots," but with dozens of consumers with their own ideas of what they want and are willing to pay for? This task requires confronting the question of whose expectations must be satisfied, and how much choice will the person being served have.

Another task in redefining quality assurance is to make choices real. Today the buzz word in our field is "choice" for individuals with disabilities. It is a sound and important concept in public policy that takes more general notions about consumer participation to the next step of real empowerment. But how well has consumer participation worked in practice in shaping individualized education plans, individual habilitation plans, individualized written rehabilitation plans, discharge plans, and so on?

Often two common and convenient practices emerge. First, surrogates have often been found to speak for the consumer. In some cases, they have been families and guardians, in others "correspondents," and in still others, agency staff. Sometimes this reliance on surrogates has worked reasonably well, but on many occasions it has also raised a real question about whose voice was being heard and whose interests were being expressed and advanced. Second, if what the consumer wanted was inconvenient or required doing things in unfamiliar ways, it was often ignored. The evidence lies in the number of children with disabilities who are still segregated in their schooling 20 years after the enactment of P.L. 94-142, despite the clear preference of their parents that they be integrated with other children; in the thousands of adults still segregated in sheltered workshops toiling endlessly at dull, repetitive tasks when many clearly want more normal work opportunities; and in the thousands of people with disabilities who are forced to live with other people not of their choosing when the only thing they have in common is a label.

One of the most significant challenges that must be faced is *making choice real* for people with disabilities. There are many dimensions to this challenge, including what is put on the menu, and how to adapt rigid governmental and bureaucratic systems to price and pay for the items on the menu. But the aspect of this challenge that will require the most profound change is truly listening to the consumer and eliciting authentic choices. We have tended to jump on the bandwagon supporting the notion of choice without adequately thinking through how substantial a change in behavior this is going to require from all of us.

## ■ Designing a Quality Assurance System

With this value-based foundation firmly in place, the key tasks for redesigning quality assurance systems are readily identified, although their implementation may challenge the culture of some organizations:

- Establish a careful process for deciding whom to entrust with the welfare of vulnerable people.
- Instill curiosity about how well the values, plans, and policies are actually being implemented.
- Inculcate a passion for the truth and willingness to hear it, and give license to all, especially consumers, to speak it.
- Emphasize spending time listening to and seeing the real condition of people's lives through their eyes rather than on examining provider processes alone.

- Teach and spread success by calling attention to the places where you find it, and take prompt and effective corrective or enforcement action against deficient performance.
- Rediscover common sense, and focus on improving the quality of services rather than extracting plans for improvement.

Implicit in these principles is the retention of traditional quality assurance functions such as licensing and certification, and the receipt, investigation, and review of complaints and incidents. However, these principles may require some systems to significantly alter the manner in which they deal with such complaints and incidents, and licensing and certification decisions.

Perhaps the most important challenge in redesigning quality assurance is finding individuals and agencies through whom public policy will be executed. In most states, community services are largely provided through contracts with private agencies, usually not-for-profits, but not exclusively so. One of the key quality assurance functions is developing a careful process of investigating the character and competence of the board members, officers, and key employees of potential licensees.

For some, provision of services and supports is a business and there is a continual tension between profit and care. Other providers may simply lack the basic competence to meet the needs of the people they serve, or lack the commitment to the values described earlier. After-the-fact monitoring may identify some of these providers, but usually only after they have inflicted substantial harm on vulnerable people. Thus, one of the most essential quality assurance safeguards is to use an examination of character and competence of licensees to ensure that we do not entrust any agency or provider with responsibility for services and supports unless we are convinced, after a careful inquiry, that they embrace these values and have a commitment to inculcate them in their staff. Once licensed, quality assurance systems should periodically and randomly audit the expenditures of agencies to determine how public money intended for services and supports is actually being spent. Few yardsticks yield as clear an indication of a provider's character than decisions to divert public money to personal gain.

The foundation for an effective quality assurance system that incorporates all the principles and traits described thus far is a genuine desire of agency leadership to know the plain, unvarnished truth about what is going on in the service system, and a willingness to follow the truth wherever it leads. This may seem such an elementary ingredient that it is hardly worth discussion, yet it is surprisingly absent in many quality assurance systems. In part, this is because the service systems have not been honest in articulating values and they dare not have quality assurance systems that regularly confront them with this dishonesty.

It is thus by design rather than by accident that it lies beyond the purview of most quality assurance systems to question what the ultimate objectives ought to be for particular clients and whether they are achievable at all in the service system as designed. It is also by design rather than by accident that, in their attempts to assure quality, quality assurance systems have rarely examined client satisfaction or client choice as a component of quality. Quality assurance systems were never designed to ask these questions about the underlying values that guide everything we do. Some so-called quality assurance activities, like risk management, have become the very antithesis of quality assurance. As these activities serve primarily to limit legal liability and provide "plausible deniability," they encourage programs to avoid confronting the reality of problems that exist. And without that, programs are often incapable of assuring basic safety, let alone aspiring to genuine quality. A quality assurance system that regularly holds up a mirror and forces recognition of the reality that exists can be a powerful tool to reinforce, disseminate, and replicate exemplary performance; it can be equally potent in identifying, curbing, and deterring abysmal performance.

For a quality assurance system to realize this potential, its work product must be made public, much in the same way that the results of health department inspections of restaurants are made public. Both the rewards of a positive survey and the opprobrium of a negative one are likely to be felt more keenly, reinforcing the potence of the quality assurance process as a behavior modification device for the service system. If quality assurance reports are to have this effect, they must also be written in plain English. Agency staff and other readers can clearly understand a report that says: "The kitchen is filthy, and the dishes are food encrusted. Clean them." On the other hand, a report that says: "Health Code Sec. 303.4 subpar (a) (ii) is violated. Conditions of participation not met," is far less clear.

With people of reputable character and competence inculcating clear values and expectations in all staff, it is far less important to develop detailed regulations governing water temperature, fiber in the diet, and square footage to monitor against. The new flexibility that exists in many government funding programs permits a more minimalist approach to regulation that relies heavily on common sense and professional judgement and less on detailed regulatory specifications. After two decades of experience with the existing regulatory system, it is abundantly plain that we have spent far too much time encouraging people to look at the ferns on the forest floor and have missed the forest itself. We need to find a way to replace fear-based monitoring, citations of deficiencies, and plans of correction with more collegial, supportive, and assisting means of improving conditions that affect the every day lives of the people being served. And in looking for ways to enhance quality for the people being served, we ought not to overlook the obvious and fail to ask them what *they* want.

*Clarence Sundram is Chair of the New York State Commission on Quality of Care for the Mentally Disabled, Albany.*

## In this issue . . .


- Redesigning Quality Assurance
- Quality Assurance, Quality Enhancement
- Challenging Tradition: Measuring Quality by Outcomes
- Balancing Inclusion, Choice, and Protection
- Quality in Community Residences: Subcommittee Report
- Quality Enhancement: A Commitment in PA
- Quality Assurance for Quality of Life in UT
- Continuous Quality Improvement in OR
- Reorientation to Quality Assurance in NY
- Service Enhancement Through Self-Examination in CT
- Performance-Based Contracting in MN
- Consumer Monitoring of Services in OK
- Gathering Quality-Relevant Data in CO
- Quality Through Direct Service Training in KS
- Improving Quality Through Parent/Self-Advocate Training
- Parent Case Management Training Promotes Quality
- Action Learning for Quality Improvement
- Resources



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The mission of the Center and Institute is to improve the quality and community orientation of professional services and social supports available to individuals with disabilities and their families. Inquiries about the Center, Institute or IMPACT can be directed to: **Institute on Community Integration, 6 Pattee Hall, University of Minnesota, 150 Pillsbury Drive SE, Minneapolis, MN 55455 • (612) 624-4848.** IMPACT is available in alternative formats upon request.

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